Data Sources & Limitations

Appendix

Prevalence and Incidence Data

Data Sources: National Health Interview Survey

Behavioral Risk Factor Surveillance System

We determined the prevalence and incidence of diagnosed diabetes in the United States by using data from the National Health Interview Survey (NHIS). This annual household survey of approximately 120,000 civilian, noninstitutionalized U.S. residents has been conducted since 1957 by CDC's National Center for Health Statistics (NCHS). The NHIS, which has a multistage probability design that has been described elsewhere (1), provides information on the health of the United States population, including information on the prevalence and incidence of disease, the extent of disability, and the utilization of health care services.

Each year, a one-sixth subsample of NHIS respondents are asked whether in the past 12 months any family member has had diabetes. If a household member has diabetes, the time since diagnosis is ascertained. In this report, diabetes prevalence was defined as the number of persons with diabetes, regardless of onset. Diabetes incidence was defined as the number of persons who were diagnosed within the past year. Three-year moving averages were used to improve the precision of the prevalence and incidence estimates. These estimates were applied to estimates of the U.S. resident population to determine the number of persons with diagnosed diabetes in the United States.

We calculated state-specific prevalence of diabetes by using data from the CDC's Behavioral Risk Factor Surveillance System (BRFSS). The BRFSS is an ongoing, monthly, state-based telephone survey of the noninstitutionalized adult population in each state that provides state specific information on behavioral risk factors for disease and preventive health practices. Respondents were considered to have diabetes if they responded "yes" to the question, "Has a doctor ever told you that you have diabetes ?". Women who indicated that they only had diabetes during pregnancy were not considered to have diabetes. We used 3-year moving averages to improve the precision of the state-specific prevalence estimates.

Data Limitations

The NHIS and the BRFSS underestimate the true prevalence of diabetes because millions of persons with diabetes do not know they have it (2). Also, NHIS proxy respondents (*i.e.*, household members responding for absent adult members) are also likely to underreport diabetes.

Mortality Data

Data Source: Underlying-Cause-of-Death Data Multiple-Cause-of-Death Data

NCHS compiles and codes information on all deaths in the United States and releases annual tapes of underlying-cause-of-death and multiple-cause-of-death data. Data on these tapes include the decedents' age, race, sex, state of residence, and the underlying cause of death. In addition to these and other variables, the multiple-cause-of-death tapes contain data on up to 20 causes of death (including underlying and contributing causes) for each decedent. Causes of death for each decedent are classified and coded according to the International Classification of Diseases, Ninth Revision (ICD-9).

We used these data tapes to extract information on deaths associated with diabetes (ICD-9 code 250) and to examine trends in diabetes as the underlying cause of death and as any listed cause of death. Among deaths for which diabetes was a listed cause, we also examined deaths for which the corresponding underlying cause was diabetic ketoacidosis (ICD-9 code 250.1), stroke (ICD-9 codes 430-434, 436-438), ischemic heart disease (ICD-9 codes 410-414), or major cardiovascular disease (ICD-9 codes 390-448).

Data Limitations

Diabetes is underreported on death certificates. Among decedents known to have diabetes, only about 40% have diabetes listed as a cause of death and only 10% have diabetes recorded as the underlying cause of death (3,4). Death certificate data therefore cannot be used to examine overall mortality among persons with diabetes. Furthermore, decedents with diabetes recorded as a cause of death are not representative of decedents known to have diabetes (3,4). Although the frequency of recording diabetes on death certificates does not appear to vary by sex, race, or ethnicity, the likelihood of recording diabetes increases with duration of diabetes, decreases with age among those with durations of diabetes of 15 or more years, is higher when comorbidities frequently related to diabetes are also recorded (e.g., ischemic heart, hypertensive, renal, cerebrovascular, and arterial disease), and is higher among those who developed diabetes before age 30 (3).

In addition, deaths and death rates may be underestimated for minority populations (5).

Hospitalization Data

Data Source: National Hospital Discharge Survey

We used data from NCHS's National Hospital Discharge Survey (NHDS) to estimate diabetes-related hospital discharges. This survey collects data on hospital discharges from a sample of short-stay, non-federal hospitals in the United States. Data collected include information on the patients' age, race, sex, length of stay, and on seven diagnoses (one primary and six secondary) and four surgical procedures. Methods used for conducting the survey have been described previously (6).

We examined hospital discharges for which diabetes was the primary diagnosis (ICD-9 code 250) and was any listed diagnosis (diabetes-related discharges). Among discharges with diabetes as a listed diagnosis, we estimated discharges for which the primary diagnosis was diabetic ketoacidosis (ICD-9 code 250. 1), stroke (ICD-9 codes 430-434, 436-438), ischemic heart disease (ICD-9 codes 410-414), or major cardiovascular (ICD-9 codes 390-448).

We also used NHDS data to examine the incidence of nontraumatic lower extremity amputation. Incident cases were defined as discharges having diabetes as a listed diagnosis and a lower extremity amputation (ICD-9 procedure code of 84.1). We excluded discharges with a diagnosis code for traumatic amputation(ICD-9 diagnoses codes 895-897).

Data Limitations

Hospitalizations related to diabetes may be underestimated by approximately 40% in the NHDS(7). Underestimation also results from the survey's exclusion of long-term and federal hospitals. Race-specific discharges are particularly underestimated because a substantial proportion of discharges are missing the racial classification, and missing values for race are not imputed (6).

Because the NHDS samples hospital discharges and not individual persons, NHDS hospital discharge rates for diabetes-related diseases and procedures may not necessarily reflect rates per person; that is, persons who are hospitalized more than once for the same condition may be counted more than once.

In 1983, Medicare instituted a prospective payment system that influenced both hospitalization practices and disease reporting on discharge records.

The incidence of nontraumatic lower extremity amputation may be underestimated by data on hospital discharges. Some amputations may be performed in outpatient settings; however, the extent to which outpatient surgery for amputation occurs is unknown.

Physician Contacts and Physician Visits, Ambulatory Care Visits to Physicians, and Outpatient and Emergency Room Visits

Data Sources: National Health Interview Survey
National Ambulatory Care Survey
National Hospital Ambulatory Medical Care Survey

These three surveys are conducted by NCHS and provide data on different aspects of the use of health care services among persons with diabetes. Details of the methodology for each survey have been described elsewhere (1,8,9).

We used the NHIS to estimate the number and rate of physician contacts and physician visits among persons with diabetes. (For a description of the NHIS, see the previous section on prevalence and incidence data.) Because estimates of physician contacts and visits include all contacts and visits regardless of purpose or reason, they reflect health service use overall, rather than use due to diabetes.

The National Ambulatory Care Survey (NAMCS) is a national cross-sectional survey conducted annually that provides data on office visits made by ambulatory patients to nonfederally employed physicians who are principally engaged in office practice (excludes anesthesiology, pathology, and radiology). Data are collected from physicians on the physician's practice characteristics, the patient and visit characteristics, and the physician's diagnoses (one principal and up to two additional diagnoses). The basic sampling unit is the physician-patient encounter or visit. We defined a diabetes visit as an ICD-9 diagnosis code of 250 listed as in any one of the three physician-diagnosis fields. In contrast to the NHIS, NAMCS data are collected from physicians, rather than from patients, telephone contacts are excluded, and diabetes had to be one of three diagnoses listed by the physician as associated with the ambulatory care visit.

The National Hospital Ambulatory Medical Care Survey (NHAMCS) is a national cross-sectional survey conducted annually that provides data on patient visits made to the emergency departments and outpatient departments of non-Federal, short-stay, and general hospitals. Clinics that specialize in radiology, laboratory sciences, physical rehabilitation, or other ancillary services are excluded from the survey. Data are collected on the patient and visit characteristics and the physician's diagnoses (one principal and up to two additional diagnoses). We defined a diabetes visit as an ICD-9 diagnosis code of 250 listed in any of the three physician-diagnosis fields.

Data Limitations

All three surveys may underestimate the use of health care services by persons with diabetes, because many persons with diabetes do not know that they have it (2).

Physician contacts and visits as measured by NHIS reflect use of health services overall among persons with diabetes, rather than use due to diabetes. Therefore, these estimates over-estimate health services used because of diabetes.

Diabetes-related visits to a physician may be underreported by both NAMCS and NHAMCS. Because persons with diabetes often have comorbid conditions, physicians may not always list diabetes as one of the three diagnoses that can be recorded. The extent of this under-reporting is unknown.

Another source of underreporting in these two surveys is the exclusion, in some cases, of encounters that people with diabetes have with some health care providers. A portion of emergency department, hospital outpatient, and ambulatory care may be provided over the telephone or by nonphysician providers but is not included in the NAMCS and NHAMCS.

Rates developed from NAMCS and NHAMCS data are not necessarily rates per person because these surveys sample patient visits and not individual persons. For example, persons who are seen in an outpatient clinic twice during the 4-week reporting period of NHAMCS would be counted more than once.

End-Stage Renal Disease Data

Data Source: United States Renal Data System

The U.S. Renal Data System (USRDS) is funded by the National Institute of Diabetes and Digestive and Kidney Diseases of the National Institutes of Health. The Health Care Financing Administration (HCFA) supplies most of the data used by the USRDS and provides expertise on data management. We used USRDS data to examine the incidence and prevalence of ESRD attributed to diabetes (ESRD-DM), because more than 90% of ESRD treatment in the United States is reimbursed by HCFA's ESRD program. ESRD is renal insufficiency requiring dialysis or kidney transplantation for survival. We defined ESRD-DM incidence as cases initiating treatment for ESRD and having diabetes as the primary diagnosis.

Data Limitations

Because we defined ESRD-DM incidence in terms of initiation of ESRD treatment, changes in incidence may have been due to changes in factors other than disease incidence, such as changes in reporting diabetes as primary cause and changes in the use of treatment. The latter may be influenced by changes in treatment availability and in the definition of treatment eligibility (10). Ascertainment of incidence cases was incomplete, because Medicare reimburses only about 90% of ESRD treatment and not all patients with the disease receive treatment (11,12).

The count of new ESRD patients for 1993 was lower than we expected on the basis of prior trends and persisted even with the usual updating of the data done by the USRDS and HCFA (13). According to USRDS, a compensatory overcount of new patients appeared to occur in 1994 and, presumably, some of these patients were truly incident in 1993. Why this occurred is not fully understood.

Disability Data

Data Source: National Health Interview Survey

We derived indicators of disability among persons with diabetes from the NHIS. (See the brief description of this data source in the earlier section on prevalence and incidence data.) Two of the major indicators of disability used in the NHIS are activity limitation and activity restriction. Activity limitation represents a long-term reduction in activity resulting from one or more chronic diseases or impairments. Reduction in activity is measured in terms of activities normal for a person's age-sex group: "ordinary play" for children under 5 years of age, "going to school" for children aged 5-17 years, "working at a job or business" or "keeping house" for persons aged 18-69) years, and independent performance of basic life activities (e. g. , bathing, eating, shopping) for persons aged 70 years and older. Persons can be categorized as being (1) unable to perform their major activity, (2) able to perform their major activity but limited in the kind or amount of this activity, (3) not limited in their major activity but

limited in other activities, and (4) not limited in activity. Our analysis examined persons limited in activity (categories 1-3), limited in major activity (categories 1-2), and unable to perform major activity (category 1). We used 3-year moving averages to improve precision of the estimates.

The other major indicator of disability, activity restriction, refers to a reduction in activity caused by either short-term or long-term conditions. Activity restriction is measured as school-loss days (for children between the ages of 5 and 17), work-loss days (for the currently employed between the ages of 18 and 69), cut-down days (days in which persons reduce or cut down on the things they usually do), and bed days (inpatient hospital days or days in which a person stayed in bed for more than half a day because of illness or injury). The total number of restricted activity days is the total number of days that a person experiences at least one of the previously described types of days. Because of small sample sizes, our analysis only presents data in 3-year moving averages on total restricted activity days and bed days.

Data Limitations

Although NHIS provides a stable source of annual estimates of disability, the survey does not sample the institutionalized U.S. population, which accounts for a significant proportion of all disability. Therefore, estimates of disability derived from NHIS underestimate the total amount of disability associated with diabetes.

In 1982, the way disability indicators were measured in the NHIS changed. For this reason analysis of these indicators began with 1983 data.

Population Data

Data Sources: 1980-1990 Bureau of the Census Population Estimates

1991-1994 Population estimates from Demo-Detail

National Health Interview Survey

We used population estimates and estimates of the diabetic population (derived by applying NHIS prevalence rates to population estimates) to calculate rates.

Data Limitations

The NHIS underestimates the true prevalence of diabetes because millions of persons with diabetes do not know they have it (2). Also, NHIS proxy respondents (i.e., household members responding for absent adult members) are also likely to underreport diabetes.

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